HIV and AIDS

Key Findings:

- National performance is improving in preventing new AIDS cases and in preventing deaths due to AIDS.
- Exceptions to this progress exist for certain age groups and among certain minority groups. Compared to the national average, new AIDS cases are 31% higher in adults ages 18 to 44, and 76% higher in black, non-Hispanic adults.

Background and Impact

Over 20 million people have died worldwide since 1981 of human immunodeficiency virus (HIV) infection and its complications.[1] In the United States, the impact of and response to HIV and AIDS has been widespread:

- CDC estimates that 850,000 to 950,000 people are living with HIV infection, and one-quarter of these people are unaware of their infection.[2]

- Approximately 40,000 new HIV infections occur each year in the United States, about 70% among men and 30% among women. Of these newly infected people, half are younger than 25.[3, 4]

- As of December 31, 2001, 467,910 deaths among people with acquired immune deficiency syndrome (AIDS) had been reported to the CDC.[5] AIDS is currently the fifth leading cause of death in the United States among people aged 25 to 44.[6]

- The President's Emergency Plan for AIDS Relief will commit $15 billion over the next 5 years to address the AIDS crisis worldwide.

Progress has been made in the past 10 years in developing drugs to fight both HIV infection and its associated complications, such as opportunistic infections and cancers.[7, 8, 9,10]

How the NHQR Measures HIV and AIDS Quality

HIV infection progressively destroys the body's ability to fight infections and certain cancers by killing or damaging cells of the body's immune system. The HIV to AIDS continuum begins

with a new HIV infection and, especially if untreated, usually proceeds to a new AIDS[i] case.[ii] Several important caveats must be considered when assessing national progress in the quality of HIV and AIDS care. Changes in HIV infection rates are a reflection of behavioral change in at-risk individuals, i.e. personal behavior, that is only partly influenced by the health system's ability to effect change. Individual and community-based intervention programs emphasize condom use and safe sex practices.[11, 12, 13] Changes in the incidence of new AIDS cases are partially affected by whether patients get appropriate treatment for HIV infection. Although a cure for HIV infection has not been identified, current drug therapies are sometimes able to reduce the amount of virus in an infected individual's body, resulting in better prognosis for HIV patients today versus 10 years ago.

The two-fold goal of the health system in providing quality services for HIV and AIDS is:

- To prevent new HIV and AIDS cases.
- To delay deaths due to AIDS.

How the Nation Is Doing[iii]

Nationwide, progress is being made in controlling the AIDS epidemic. Performance is improving in reducing new AIDS cases and AIDS mortality, although new data presented in below show some increase in AIDS incidence rates. The appearance of new drugs—protease inhibitors—in 1995 and 1996 has contributed to this progress. In addition to drug therapies, progress has been made in HIV testing products and procedures that address the problem of the 200,000 people unknowingly infected with the virus.

- New AIDS cases, or AIDS incidence rates, climbed rapidly from the early 1980s and peaked in the early 1990s.[iv,14]

[i] The term AIDS applies to the most advanced stages of HIV infection. CDC developed official criteria for the definition of AIDS and is responsible for tracking the spread of AIDS in the United States. CDC's definition of AIDS includes all HIV-infected people who have fewer than 200 CD4 positive T cells (abbreviated CD4+ T cells) per cubic millimeter of blood. Healthy adults usually have CD4 positive T-cell counts of 1,000 or more. In addition, the definition includes 26 clinical conditions that affect people with advanced HIV disease. Most of these conditions are opportunistic infections that generally do not affect healthy people. In people with AIDS, these infections are often severe and sometimes fatal because the immune system is so ravaged by HIV that the body cannot fight off certain bacteria, viruses, fungi, parasites, and other microbes. See http://www.niaid.nih.gov/factsheets/hivinf.htm for more information.

[ii] *AIDS cases reported through December 2001*. Year-end edition. Vol. 13, No .2. CDC Web site http://www.cdc.gov/hiv/stats/hasr1302.pdf; accessed 4/2/03).

[iii] Adjusting for known contributing factors, such as gender, age, and insurance status (multivariate analysis), would allow for more detailed exploration of the data, but this generally was not feasible for this report. Any adjustments that were done are noted in the detailed tables. The data presented in this report do not imply causation.

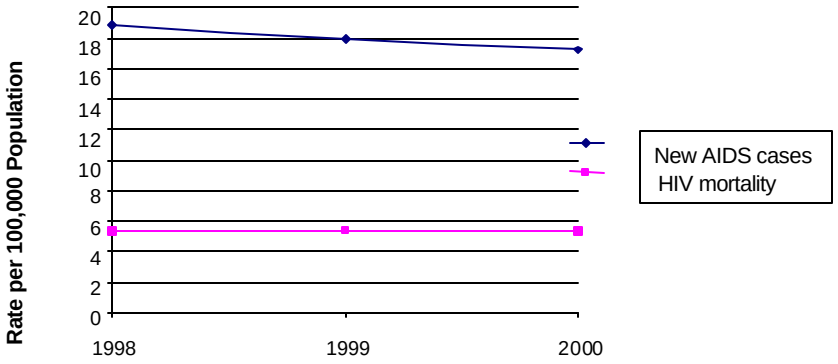
[iv] Centers for Disease Control and Prevention, 2001, ibid.

- The number of new AIDS cases decreased by 8.5% between 1998 and 2000. However, very recent data reflect a 2.2% increase in the AIDS incidence rate for 2002.[v,15]

- Mortality rates due to AIDS have been declining steadily since 1995. The estimated annual number of AIDS-related deaths in the United States fell approximately 70% from 1995 to 2001.[vi,16] Data for 2002 show a 5.9 % decline in AIDS deaths.

Figure 12 demonstrates that while there was a decline in the rate of new AIDS cases between 1998 and 2000, the rate of HIV mortality stayed virtually the same during that time.

Figure 12. New AIDS Cases and HIV Mortality



Source: Centers for Disease Control and Prevention, National Center for HIV, STD and TB Prevention, HIV Surveillance System

New AIDS infection rates vary by age, with adults between 18 and 44 being infected at a rate that is 31% higher than the national average. Differences in AIDS infection rates are even more marked when broken down by ethnicity. Black, non-Hispanic adults contract AIDS at a rate that is 76% higher than the national average of 17.2 cases per 100,000.

[v] HHS, CDC (National Center for HIV, STD, and TB Prevention). HIV diagnoses climbing among gay and bisexual men. NCHSTP Press Release, July 28, 2003.

[vi] CDC, 2001, ibid.

What We Don't Know

Clinical care for HIV and AIDS is changing rapidly, making it difficult to evaluate national performance in quality of care and achieve consensus on national measures. Inclusion of quality measures in this report is limited by availability of national data.

Virtually all national data on HIV and AIDS are related to incidence and prevalence, not treatment. The Adult Spectrum of Disease and Pediatric Spectrum of Disease surveys run by the CDC are the start of a tracking system for HIV and AIDS. However, these surveys were not designed to provide national or sub-national estimates for quality of care for people living with HIV and AIDS.

One area where the health care system may have an impact on the primary prevention of HIV infections is in preventing transmission of HIV from mothers to their infants. The CDC recently recommended routine HIV testing for all patients, especially pregnant women.[17]

Little has been done at the national level to develop and test potential measures for tracking the quality of care for the many opportunistic infections in HIV and AIDS patients. This may not involve the development of major new databases but, rather, using and enhancing existing national databases to examine care for the HIV and AIDS patient subpopulation.

Although protease inhibitors slow the progression of HIV, they also often result in significant side effects, including lipodystrophy, diabetes mellitus, hypercholesterolemia, etc. At present there are no data that would allow us to track such side effects, yet these side effects are important in the lives of HIV-infected individuals.

Some interventions to address quality of life for people living with HIV and AIDS have been effective.[18, 19] However, more information is needed on the types of behavioral and cognitive interventions that can be implemented and supported through the health system to improve quality of life.

What Can Be Done

Additional development of national quality measures for HIV and AIDS is needed. As described in the Executive Summary and Introduction to this report, the NHQR measure set is based on measures with regularly available national data sources.

Beyond currently available incidence and prevalence data, there is a need for improved information on quality and outcomes data for HIV and AIDS. There have been some efforts in this area, but they are based on single-point-in-time data collections. For example, the HIV Cost

and Services Utilization Study (HCSUS) was a national study of HIV and AIDS care conducted between 1996 and 1998 that used a national probability sample of 4,042 people with HIV disease from 145 health care providers in 28 metropolitan areas and 51 providers in 25 rural areas. Some of the findings from HCSUS[vii] include:

- The researchers estimated total costs for treating all people with HIV during the first 6 months of 1996 at $6.7 billion and the average per person cost at $20,000.

- The researchers examined self-reported antiretroviral therapy (ART) use among 2,267 HCSUS participants in 1997. About 90% of participants reported use of any ART, and 61% reported use of the more advanced, currently recommended HAART (highly active ART: three or more drugs, including at least one protease inhibitor or nonnucleoside reverse transcriptase inhibitor).

- Only half of patients discussed some aspect of end-of-life care with their doctor, and 38% completed an advance directive. Patients were nearly six times more likely to complete an advance directive after a discussion with their provider.

[vii] For more information about HCSUS, see www.ahrq.gov/data.hcsus.htm.

Effectiveness

HIV/AIDS

List of measures

HIV and AIDS

Measure Title	National	State
AIDS prevention:		
Outcome: New AIDS cases per 100,000 population (age 13 and over)	Table 1.46a (00) Table 1.46b (99) Table 1.46c (98)	N/A
Management of HIV and AIDS:		
Outcome: HIV-infection deaths per 100,000 population	Table 1.47a (00) Table 1.47b (99)	Table 1.47c (00)

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